

NPM #12: Percentage of newborns who have been screened for hearing before hospital discharge.

Impact on National Outcome Measures: The WSB Program was created to promote early hearing detection and intervention statewide and to meet the goals as outlined in Healthy People 2010; the 2000 Statement of the Joint Committee on Infant Hearing; the American Academy of Pediatrics Policy Statement on Newborn Hearing Screening; and Wisconsin Statute 253.115.

a) Report of 2002 Major Activities

1. Outreach and Public Education—Enabling Services—Pregnant women, mothers, and infants

A screening brochure called “A Sound Beginning for Your Baby” was made available in both English and Spanish. See Appendix 7. WSB provided communication to over 3,000 EHDI stakeholders through a quarterly newsletter. Family physicians were provided a copy of “Babies and Hearing Loss: A Guide for Providers about Follow-up Medical Care”. See Appendix 8. All WSB documents are available at www.perinatalweb.org.

2. Home Births Initiative—Direct Health Care Services—Pregnant women, mothers, and infants

The home birth outreach program enables families access to hearing screening through portable equipment used by midwives. Available in Dane and Brown Counties, this initiative screened 101 babies in 2002. Educational materials have been adapted to meet the needs of this population.

3. WSB/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

Working with the NBS program, the WSB program revised the blood filter paper cards to add UNHS screening calls.

4. Statewide "Champions" Network—Infrastructure Building Services—CSHCN

In February 2002, professionals and parents participated in a two-day event to share current "best practice" information. Each participant developed a written "commitment to action". In August 2002, WAPC hosted four teleconferences and invited the champions to participate to discuss success and barriers to achieving individual commitments.

5. Birth to 3 Technical Assistance Network—Infrastructure Building Services—CSHCN

A network of 16 early intervention providers was convened for an annual two-day meeting to further define their program mission and consultant roles regarding UNHS.

6. Support Services for Parents—Enabling Services—CSHCN

A parent summit was convened to bring parents together to discuss support services for their deaf or hard of hearing child's early years. A resource Notebook titled *Babies and Hearing Loss: An Interactive Notebook for Families with a Young Child who is Deaf or Hard of Hearing* was developed. See Appendix 9.

7. Wisconsin EHDI—Tracking Referral and Coordination System (WE-TRAC)—Infrastructure Building Services—CSHCN

Upon full intervention set for 2005, the Wisconsin EHDI—Tracking Referral and Coordination (WE-TRAC) system will collect hearing screening results on all babies via the Newborn Blood Collection card, and web-based data collection and referrals for out-patient re-screens, diagnosis and intervention services. WE-TRAC will link other data systems and providers including primary care providers (medical home).

b) Current 2003 Activities

1. Support Services for Parents—Enabling Services—CSHCN

Parent-to-Parent Network Summit: In January 2003, 25 families from around the state of Wisconsin came together for a two-day Parent-to-Parent Network Summit. The top three recommendations from this group of parents were: 1) An annual conference for parents with children who are Deaf or Hard of Hearing, 2) A statewide website with regional and local resources, activities and contacts, and 3) A parent-to-parent network/group.

The final manuscript is available free of charge to Wisconsin families and available at www.infanthearing.org.

Annual Conference for Families of a Deaf or Hard of Hearing Child: This first annual conference scheduled for June 27-30, 2003 was a direct outgrowth of the Parent to Parent Network Summit recommendations. This conference has been planned by parents of children birth to 21 years of age who are deaf or hard of hearing and sponsored by the Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH) - Outreach Program with support from DPI, DHFS and WSB.

2. Wisconsin Sound Beginnings (WSB)/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

Regular updates regarding hearing screening are provided by the WSLH to hospital contacts through the WSLH NBS Program Newsletter. According to data collected from the blood card from April 30, 2002 - April 10, 2003, 49,710 (92%) of babies were screened; of those babies screened, 795 (1.6%) were referred; 2,831 (5%) of cards had incomplete information; 154 (0.3%) refused screening.

3. Outreach/Public Education—Enabling Services—Pregnant women, mothers, and infants

WSB provides regular communication to over 3,000 EHDI stakeholders through a quarterly EHDI newsletter and is available at www.perinatalweb.org.

4. The Wisconsin Pediatric Audiology Training—Infrastructure Building Services—CSHCN

This training consisted of three parts:

- a) A web-based curriculum, including PowerPoint presentations, readings, weekly chat sessions, weekly quizzes.
- b) The pre-convention workshop.

c) The general convention (March 14-15).

Those individuals who completed the training qualified to be part of a statewide list of providers that will be widely distributed to physicians and hospitals so that initial referrals to appropriate audiologists can be made.

5. Birth to 3 Technical Assistance Network—Infrastructure Building Services—CSHCN

The network of consultants provided regional training and TA to local Birth to 3 programs.

6. WE-TRAC—Infrastructure Building Services—CSHCN

Beginning January 2003, a WE-TRAC Project Manager was hired and WE-TRAC entered the pilot phase. Eleven hospitals are currently participating in the pilot. These participants represent a mix of facilities ranging from small rural to large urban and collectively handled almost 8,000 births in 2002.

c) 2004 Plan/Application

1. Outreach/Public Education—Enabling Services—Pregnant women, mothers, and infants

WSB will continue to make available outreach materials related to the importance of screening such as "A Sound Beginning for Your Baby" to hospitals and providers through necessary reprinting. WSB will also continue to provide regular communication to over 3,000 EHDI stakeholders through the quarterly EHDI newsletter and provide regular updates to WIAAP and WAFP membership through their newsletters and list serves. WSB will distribute the "quick guide" for the primary care provider regarding next steps in the care of a child with diagnosed as deaf or hard of hearing.

2. Support Services for Parents—Enabling Services—CSHCN

The Second Annual Conference for families with deaf, deaf-blind, and hard of hearing children will be organized to occur in the winter/spring of 2004.

WSB has begun promotion of the Parent Notebook to local Service Clubs and Foundations in hopes of having the Notebook translated and printed in Spanish by the end of 2004.

As an outgrowth of the 2003 Parent Summit, a lead parent point of contact was chosen for each DPH region. This lead parent will organize a regional parent to parent activity with support from the WSB and the Wisconsin Personnel Development Project (WPDP) before March 2004.

3. Birth to 3 Technical Assistance Network—Infrastructure Building Services—CSHCN

Promotion of the Birth to 3 Technical Assistance Network will occur throughout 2004. The network will continue to provide critical TA to local Birth to 3 programs. The network of consultants will receive ongoing training, TA and support in 2004. Discussions will continue with key partners to provide the Birth to 3 Technical Assistance Network with oversight and direction as well as to continue to foster support and commitment to the importance of the existence and function of this network.

4. WSB/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

WSB will continue to provide regular updates regarding hearing screening through the WSLH NBS Program Newsletter.

5. UNHS Implementation Work Group—Infrastructure Building Services—CSHCN

The Work Group will continue to meet quarterly to work on priorities determined a part of its strategic planning process for 2004.

6. WE-TRAC—Infrastructure Building Services—CSHCN

Activities in 2004 will focus on the following: statewide use of WE-TRAC by hospitals and re-screening sites; the addition of audiologists as users; the development of Birth to 3 user requirements and software development; expansion of WE-TRAC to primary care providers.